



Introduction

Birth defects are the leading cause of infant mortality in the United States, accounting for approximately 20 percent of infant deaths annually. Each year, almost 150,000 babies are born with a congenital malformation. Because of the morbidity and long-term disability associated with these conditions, birth defects are also the fifth-leading cause of years of potential life lost.ⁱ State public health agencies can help improve birth outcomes through administering birth defects surveillance programs and registries, which collect and share valuable information about birth defects trends with policymakers, providers and researchers.

Collecting data through birth defects surveillance programs administered by state public health agencies is integral to the promotion and protection of newborn health and can ultimately contribute to improved birth outcomes.ⁱⁱ The information made available through monitoring helps to identify rates and trends and improves access to care for affected children and families. Such programs also provide data for etiologic studies and prevention initiatives. When combined with the efforts of other agencies, organizations, and researchers, the data from state surveillance programs and registries could also help to reveal the origins of birth defects. Ultimately, these activities can help minimize the physical, social and financial burdens faced by children and families affected by birth defects.

Although many states have made progress in monitoring birth defects, several obstacles to further improvement remain. These include:

- State budget deficits and federal funding constraints.
- A lack of formal partnerships between and amongst state health agencies and other departments, agencies and organizations around data sharing.
- The implications of federal laws around privacy for state regulations.
- Integration of technology with existing surveillance mechanisms.
- The capacity of states to implement quality assurance measures and evaluation activities of birth defects surveillance.

This issue brief provides an overview of state public health agencies' roles in birth defects surveillance and outlines opportunities for state public health agencies to strengthen existing systems. It also provides supporting state examples.

Importance of Birth Defects Surveillance

Surveillance refers to “the ongoing systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice” and “the application of these data to prevention and control.”ⁱⁱⁱ Birth defects surveillance in the U.S. began nearly 80 years ago, when New Jersey enacted legislation mandating reporting of congenital anomalies.

Today, 43 states and the District of Columbia are collecting data on birth defects; 42 of these programs are based in state public health agencies. Of these 43 states, approximately 85 percent also provide families referrals to health services, prevention programs, and intervention

programs. Eighty percent of surveillance programs are legislatively mandated at the state level. Over half of the states currently collecting data do so through at least one “active” ascertainment component, where program staff seeks cases from hospitals and clinics; approximately 40 percent use only “passive” case ascertainment, relying on third parties to report cases to the program. An additional two states have begun to implement surveillance programs but are not yet collecting data, while four states do not have any system in place to track birth defects.

Birth Defects and Public Health

Birth defects monitoring is consistent with the goals of public health. The activities of surveillance programs and registries allow state public health agencies to carry out the essential functions of public health and potentially help prevent infant mortality. Through data collection, surveillance programs are able to assemble information for studies that will help identify social, behavioral, and environmental factors that create risks for developing fetuses and increase the likelihood of birth defects in newborns. In addition, tracking the prevalence of congenital malformations helps states to identify local rates and trends and recognize clusters of cases that may be due to environmental exposures. These information-gathering and analysis activities promote the development and implementation of new policies. Preventing birth defects through surveillance will also contribute to long-term budget savings, as it is substantially less expensive to fund prevention programs than to treat chronic conditions.

The Metropolitan Atlanta Congenital Defects Program (MACDP), a population-based system administered by the Centers for Disease Control and Prevention (CDC) since 1967, has served as a model and resource for state programs. The program’s data have been used in epidemiologic studies of trends in such defects as hypospadias, heart defects and neural tube defects. The data have also been used to study possible risk factors, including the effects of maternal diabetes and maternal substance

abuse, and to evaluate prognostic factors for morbidity and mortality in children born with birth defects.

The prevention efforts of state public health agencies are not limited to implementation and oversight of birth defects surveillance programs. Monitoring programs facilitated by health agencies offer the potential to build linkages with other state agencies. For example, working with environmental agencies promotes greater understanding of the impact of exposures such as air pollution and pesticides on newborn development. Collaborating with divisions of Children with Special Health Care Needs (CSHCN) can facilitate referral systems and foster a more streamlined approach to caring for infants with birth defects. By linking birth defects surveillance programs with other agencies, state public health agencies can maximize the contribution of monitoring to birth defects prevention and improve the quality of life of children and families affected by these conditions.

The Role of Birth Defects Legislation

Currently, 43 states have some kind of mandate supporting birth defects monitoring activities. These laws serve many important functions in state surveillance programs, including designation of agency authority, identification of program goals and priorities, definition and terminology to guide data collection, and development of privacy protocols.^{iv} Birth defects laws can also promote program sustainability by earmarking specific state monies to ensure the availability of funding to support surveillance activities. Careful attention to the language of the laws mandating birth defects surveillance can ensure that laws are broad enough to accommodate the changing needs of public health, while still providing clear guidance to the state health agencies in their surveillance activities.

To date, there are no national standards for birth defects surveillance. While there can be many differences among state programs as a result, the flexibility afforded states in their design, implementation, and administration allows birth

defects surveillance programs to be tailored to the specific needs of individual states.

Obstacles and Policy Challenges

There have been many improvements in states' efforts to monitor birth defects in recent years. In addition to those states that have newly implemented surveillance programs, many states have augmented their existing systems through such measures as web-based reporting, incorporation of referral and intervention services, and involvement in newer projects like the CDC's Environmental Public Health Tracking Program. As detailed below, many obstacles remain that may prevent additional critical improvements in tracking birth defects.

Funding Concerns

States are using a number of sources to fund their birth defects surveillance programs and related prevention activities. The most commonly used funding sources include CDC grants, general state funds, and Title V block grant appropriations. Some states are using alternate types of funding, such as genetic screening revenues and grants from private foundations and the March of Dimes. The ability to support birth defects activities through diversified funding sources may be particularly important during periods of fiscal uncertainty and budget deficits, and may help states to sustain their monitoring activities.

CDC currently funds 65 percent of existing birth defects surveillance programs. Their grants constitute anywhere from ten to 100 percent of a state's funding sources. Although funding through CDC and Title V are often critical components of sustaining a state's birth defects surveillance activities, they are limited in their capacity to be sole funding sources.

Formal Partnerships

States have flexibility in determining the overall structure and design of their surveillance programs. Despite their critical

role in preventing birth defects, not all state public health agencies pursue diverse formal partnerships. Some states partner only with hospitals or universities, whereas others have multiple and varied partners ranging from advocacy groups to community nursing services.

Two areas where partnerships are extremely valuable to state birth defects surveillance programs are environmental agencies and CSHCN agencies. Without these partnerships, valuable opportunities to better understand birth defects, as well as to improve the quality of life for children and families, may be missed. A lack of formal structures to permit such collaborations is one barrier faced by states seeking to link their birth defects surveillance efforts with other agencies. It is not uncommon for overlapping departments to be located within separate agencies. States public health agencies are also confronted by difficulties in data-sharing regarding security and patient confidentiality.

In 2002, CDC established its National Environmental Public Health Tracking Program (EPHT), committed to the collection and analysis of environmental hazards, exposures to those hazards, and related health effects.^v Of the 21 states receiving EPHT grants, nine receive funding for projects linking environmental, exposure and health effect data. Examples of state projects include linking birth defects data with data on water quality and air pollution and linking different surveillance and monitoring programs to form statewide tracking networks.

The Colorado Responds to Children with Special Needs (CRCSN), a program established in 1989 to monitor and prevent birth defects, is an example of a state public health agency utilizing partnerships to enhance the identification, referral and treatment of CSHCN. One of the program's specified goals is "to help connect children and families with early intervention services in their communities."^{vi} The Colorado Department of Public Health and Environment achieves this through partnerships with community agencies, including local health departments, community nursing services, and early childhood intervention programs. A representative, such as an experienced parent, calls or visits with families

dealing with birth defects to facilitate connections with services that include developmental evaluations, specialty medical care, parent support groups, and financial assistance. A survey of families indicated that parents found the interaction with a local representative to be helpful and valuable.

Technology Integration

The process of integrating technology with existing public health activities is often slow at the state agency level. This can be attributed to a number of causes, including funding constraints and a lack of qualified staff which can limit the capacity to adopt new technologies. Another barrier for state public health agencies is the degree of technical sophistication in hospitals and other reporting sources. It is difficult to implement web-based reporting and computerized data analysis systems if reporting sources do not already have the means to support such activities.

It is important that technology become a part of states' birth defects surveillance activities in spite of these limitations. The reporting process in particular is one key area where technology would greatly improve birth defects monitoring. Paper-based reporting is not only cumbersome for hospitals and physicians, but increases the potential for reporting errors. In addition, it is difficult to monitor compliance with state-mandated reporting requirements. Computerization of birth defects surveillance, however, requires careful attention to issues related to data transmission and entry modes, systems access, administration and backup, and linkages with other databases.

States that are implementing Internet-based reporting systems demonstrate the benefits of such technology over traditional forms of reporting. The Virginia Department of Health's Virginia Infant Screening and Infant Tracking System (VISITS) tracks the screening results from four programs and services administered by the state public health agency, including the state's birth defects registry, using an integrated database system to develop and maintain a single record for each child identified by at

least one of the participating programs. Computerization of reporting in the New York State Department of Health's Congenital Malformations Registry has helped to identify cases that hospitals had previously failed to report.

The integration and use of technology is one potential way to facilitate monitoring of partner compliance and identify reporting problems without incurring substantial costs. State public health agencies can achieve standardization, monitor timeliness and case duplication, and improve efficiency through computerization of birth defects surveillance activities.^{vii} Simultaneously, there are valid concerns regarding the security of such options that must be addressed before wide-scale systems can be implemented.

Quality Assurance and Evaluation

Particularly where there are multiple partnerships and legislatively mandated reporting requirements, it is important that states be able to monitor surveillance activities and enforce compliance. Such oversight protects the validity and usefulness of the data collected through birth defects surveillance programs.

The New Jersey Department of Health and Senior Services' New Jersey Special Child Health Services Registry engages in many quality assurance activities to ensure the integrity of its data. By requiring birth defects reporting as a part of the state's hospital licensing standards, New Jersey provides a distinct incentive to its hospitals to notify the Department of Health and Senior Services when infants are born with congenital defects. In addition, master's-trained nurses conduct annual audits of birth records at all maternity hospitals and other facilities providing pediatric services. These activities are augmented by a manual review of birth and death files and infant death certificates, and by coordinated activities with other screening programs within the agency, such as newborn hearing.

Privacy & Confidentiality

Privacy and confidentiality are important considerations for state public health agencies

and the programs they administer. This is especially true for disease surveillance programs that handle sensitive personal information or engage in data sharing. The passage of the Health Insurance Portability and Accountability Act (HIPAA), for example, has heightened awareness of and concern for privacy issues, particularly at the state level. Confusion over HIPAA legislation and requirements of the Privacy Rule has inhibited certain state activities in birth defects surveillance, particularly data sharing between state public health agencies and covered entities. Such activities, however, are critical to research, improving public health interventions, protecting health and promoting cost savings.^{viii} It is important that states and their partners recognize that the Privacy Rule permits disclosure of protected health information for public health activities such as birth defects surveillance programs and registries.

Another federal law with significant implications for state birth defects surveillance activities is The Family Educational Rights and Privacy Act (FERPA). Collaboration with education agencies can be effective and necessary for birth defects surveillance programs, as educational records may contain information vital to the coordination of follow-up and early intervention services.^{ix} Designed to protect the privacy of student education records, FERPA requires written permission from the parent, or student over the age of 18, to release any information from the student's record. While there are certain conditions under which the information contained in educational records can be released without consent, the law is a significant impediment to building partnerships between states' birth defects surveillance programs and the school system. Some states have established memorandums of understanding between public health and education agencies to facilitate this data-sharing.

Conclusions

Despite advances in medical care that have improved birth outcomes overall, many infants continue to die each year because of birth defects. Those who survive may face a lifetime of disability and significant medical expenses. Birth defects surveillance is an opportunity for state public health agencies to take an active role in lowering prevalence rates, promoting early identification of children in need of special services, and ultimately preventing birth defects in the future.

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The Association of State and Territorial Health Officials is the national nonprofit organization representing the state and territorial public health agencies of the United States, the U.S. territories, and the District of Columbia. ASTHO's members, the chief health officials in these jurisdictions, are dedicated to formulating and influencing sound public health policy, and assuring excellence in state-based public health practice.



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ⁱ Centers for Disease Control and Prevention. "Birth Defects." Available at <http://www.cdc.gov/ncbddd/bd/default.htm>. Date accessed: 06/08/04.

ⁱⁱ Trust for America's Health. "Birth Defects Tracking and Prevention One Year Later: One Step Forward, Two Steps Back?" April 2003.

ⁱⁱⁱ Centers for Disease Control and Prevention. "Comprehensive Plan for Epidemiologic Surveillance." Atlanta, GA : Centers for Disease Control and Prevention, 1986. Available at <http://ehp.niehs.nih.gov/members/1995/Suppl-3/goldman-full.html>. Date accessed: 07/02/04.

^{iv} National Birth Defects Prevention Network (NBDPN). *Guidelines for Conducting Birth Defects Surveillance*. Sever, LE, ed. Atlanta, GA: National Birth Defects Prevention Network, Inc., June 2004.

^v Centers for Disease Control and Prevention. "Environmental Public Health Tracking Program." Available at <http://www.cdc.gov/nceh/tracking/program.htm>. Date accessed: 7/3/04.

^{vi} Colorado Department of Public Health and Environment. "What is Colorado Responds to Children with Special Needs?" Available at <http://www.cdphe.state.co.us/dc/crcsn/crcsnhome.asp>. Date accessed: 8/3/04

^{vii} National Birth Defects Prevention Network (NBDPN). *Guidelines for Conducting Birth Defects Surveillance*. Sever, LE, ed. Atlanta, GA: National Birth Defects Prevention Network, Inc., June 2004.

^{viii} Association of State and Territorial Health Officials. "Information Management for State Health Officials: Data Sharing with Covered Entities Under the HIPAA Privacy Rule." 2004.

^{ix} National Birth Defects Prevention Network (NBDPN). *Guidelines for Conducting Birth Defects Surveillance*. Sever, LE, ed. Atlanta, GA: National Birth Defects Prevention Network, Inc., June 2004.